1995

An evaluation of early intervention efforts with severely and profoundly retarded infants and young children

Theresa A. Stacy

AN EVALUATION OF EARLY INTERVENTION EFFORTS WITH SEVERELY AND PROFOUNDLY RETARDED INFANTS AND YOUNG CHILDREN

A Project

Presented to the

Faculty of

California State University,

San Bernardino

In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

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ABSTRACT

This report is about a study that explored the impact of the services provided by the "Early Start" program at Inland Regional Center, an agency serving the developmentally disabled, on the development of severely and profoundly retarded children between three and six years of age. The functional skill gains of children who received services through the agency's "Early Start" program were compared with those of children who were assigned to a regular case management unit after the agency intake process. Even though the children in the "Early Start" group were younger and more medically impacted than those in the regular case management unit, the "Early Start" children averaged more increases in the targeted functional skills than the other group, though not at a statistically significant level. This study adopted a positivist approach, and the data is descriptive in nature.

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INTRODUCTION AND LITERATURE REVIEW

Many theorists such as Piaget (1952), Kagan (1984), Erikson (1963), Freud (1946), Bowlby (1969, & 1982), and Ainsworth (1973) have focused on the developmental processes of infants and young children. They have analyzed the various physical, emotional, cognitive and social changes which occur during the course of growth and development, and have developed theoretically-based explanations for these normal progressions. This knowledge has been used to construct tests of development such as The Vineland Social Maturity Scale (Doll, 1953), The Vineland Adaptive Behavior Scale (Sparrow et al., 1984), The Bayley Scales of Infant Development (Bayley, 1969), and The Denver Developmental Screening Test (Frankenberg and Dodds, 1968) which have been standardized on normal children. These tests are used to analyze a child's development patterns for deficient areas needing a remedial focus, and to determine the severity of their deficits.

Relatively little attention has been given to the children who show large deviations from expected norms, other than to note that such differences occur. The majority of the attention which has been concentrated in this area has focused on those who are "at risk," those who have delays which have the potential for correction

with the provision of early intervention services. Many of the studies of "at risk" children have focused on the efficacy of early intervention efforts with children of socially disadvantaged families who have various types of environmental deprivation (Andrews et al., 1982), (Garber and Heber, 1981), (Gray et al., 1982), (Zigler and Anderson (1979), (Schweinhart and Weikart, 1980), (Wasik et al., 1990), (Hupp, 1991), (Martin et al., 1990), and all have reported significant gains resulting from such efforts. These studies have provided the impetus for further early intervention attempts.

Another major focus of attention in this area has been with children who are at risk due to biological factors such as low birth weight or pre-term delivery (Murray, 1988), (Widmayer and Field, 1981), (Bromwich and Parmelee, 1979), (Beckwith, 1988), (Leib et al., 1980), (Field et al., 1980), (Rauh et al., 1988). These studies also generally show that significant gains can be made with early intervention and treatment in the majority of cases. Many of these infants tend to have problems resulting from immature development rather than abnormal development, and treatment of a basically biologically sound, albeit underdeveloped, child has a good chance of success with today's technological and medical advances.

Problem Statement

Relatively few efforts have been made to systematically examine the developmental course of severely handicapped children who have little potential for normal development, or the intervention efforts needed to optimize that development during the early formative years. These children display significantly lower intellectual functioning and impaired adaptive behavior relative to normal children. The majority of these children have conditions which can be traced to problems in prenatal development or complications in the perinatal and postnatal periods, with a minority having problems for which no discernable cause can be determined (Guralnick and Bricker, 1987).

One of the reasons this group has received so little attention as a unit is that it is difficult to find a conceptual frame to encompass the heterogeneous population that is referred to when one uses the term severely handicapped. It includes people who have sensory impairments of vision and/or hearing, gross and fine motor impairments, neuromuscular impairments, cognitive impairments, social/emotional impairments, and communication/language impairments, as well as those who have various combinations of these conditions. Even if this conceptual barrier is overcome, an additional

problem blocking research efforts in this direction is the lack of appropriate measurement instruments to record the developmental gains of this population. Additionally, as Whitman et al. (1990) point out, a scientifically valid instructional model for the severely handicapped individual does not yet exist.

Utley (1986) discusses these issues and notes that

> "many states require a description of the severely handicapped population that includes a traditional measurement requirement even though administration and interpretation of these measures is invalidated by the presence of physical and/or sensory handicaps." (p. 23)

She believes that a basic criterion of any definition of the severely handicapped should be that they are functionally impaired in the severe to profound range of mental retardation with or without any of the additional impairments. The use of this perspective would make it possible to standardize the definition of a severely handicapped child, regardless of the type(s) of impairment(s) present. The focus could then be placed on scientifically valid ways of increasing the functioning level of the child, and of evaluating the effectiveness of those efforts.

Intuitively, it makes sense that an understanding of the different factors which affect these children's functioning and of the differential effects of varied

levels of these factors on their development could help clarify the learning processes of severely impacted children as well as those of normal children. Increased knowledge of the specific biological problems that lead to various developmental delays could expand our understanding of the role that physiology plays in the learning process. Similarly, knowledge about how specific environmental manipulations affect the differentially impaired biological systems of children could enhance our awareness of the limits of such influences on the development, maintenance, and alteration of different behaviors and skills. Research already done in these areas has provided us with some information, but no one has yet managed to organize this knowledge and ground it in scientific theory.

Information obtained from further research in these vital areas could provide the necessary foundation for the development of a more comprehensive theoretical framework of child development, more appropriate intervention methods to optimize development, and more appropriate measurement instruments to measure a child's developmental deficits and/or progress. This would make it possible to intervene more effectively with children to maximize their potential, as well as make it more feasible to monitor whatever small progress is achieved

through intervention efforts. Brockman et al. (1988) stress that knowledge of whether inherent deficits, environmental factors, or a combination of both is interfering with development is essential for effective program planning and intervention with these children.

Bijou (1992) has examined the theoretical concepts of mental retardation proposed by researchers during the past century to determine which concept makes the most sense in the light of our present knowledge. He suggests that the restricted development view which "posits that a person with mental retardation is one with a relatively small repertoire of behavior to the point of being unable to adapt to society without assistance" (p. 317) is the most workable theory. The limited behavior repertoire is caused by restrictions in development due to disadvantaged sociocultural conditions, biomedical pathologies, or combinations of both. He notes that this theory has the advantage of conforming to a behavior theory of human development. This allows those doing research with the mentally retarded to take advantage of the large body of literature developed around behavior theory in the design of habilitation and rehabilitation programs for this population. Evaluation of intervention programs could also be approached from this perspective.

In discussing early intervention programs for severely handicapped children, Dunst (1986) notes how lack of a theoretical conceptualization as a basis for program design and evaluation leads to the adoption of several assumptions that are typically made to facilitate the evaluation process. He observes that it is often assumed that most children benefit equally from early intervention efforts, that the degree of involvement and intensity of intervention is similar for all program participants, that the duration and amount of treatment provided to the children are of sufficient magnitude to demonstrate or refute the efficacy of early intervention, and that the early intervention efforts of the program are the principle or only interventions provided to the program participants. Measurements of the effectiveness of early intervention efforts somehow need to become less global and more individualized to correct for the problems generated by these assumptions.

Use of a behavior theory framework in the design of program evaluation measurement instruments may help to accomplish that goal. Infants and young children, particularly those who are severely handicapped, have little or no ability to communicate their cognitions or feelings other than through their behavior. They are also in the early stages of their development, and the

different experiences that impact their behavior do so in a more straightforward and simplified manner, since their ability to assimilate and process the complexities of their experiences is reduced. Thus, behavior theory is the most logical framework to use in the design of evaluation tools and in the analysis of the efficacy of interventions with this population. Instruments using this framework as a foundation could focus on the amount and type of behavioral changes that occur as a result of specific types and amounts of interventions, accounting for physical limitations, and provide scientifically valid information to assist in clarifying the learning processes of these, and possibly all, children.

Problem Focus

This research was undertaken to evaluate the impact of the early intervention services provided by the Part H "Early Start" program of Inland Regional Center on the development of the severely handicapped child. Inland Regional Center is an agency which serves the geographic areas of San Bernardino and Riverside Counties. It is one of twenty one non-profit agencies under contract with the State of California to provide lifelong diagnostic, intervention, and case management services for individuals who are developmentally disabled, or who are at risk of such a disability. A developmental

disability is one that originates before the age of eighteen, continues or is expected to continue indefinitely, and causes a substantial handicap. Those covered by this term include people who are diagnosed with mental retardation, cerebral palsy, epilepsy, and autism, as well as those with problems which manifest similar symptoms to these conditions.

Individuals whose families request services from Inland Regional Center undergo an initial evaluation process to determine the nature and severity of their disability. Those found to have conditions meeting the agency's eligibility criteria noted above are referred to appropriate units in the agency based on their age at intake. Children who are initially evaluated between birth and three years of age and who are found to have a clear or a potentially qualifying disability due to specified risk factors are referred to the agency's "Early Start" program. This is a special agency unit which provides interventions designed to maximize the development of young children during their critical formative years in order to prevent or minimize the disabling effects of their particular conditions. It provides case management services including evaluation, counseling, referral, support, parent training and education, purchase of special services, and advocacy.

At the age of three, after receiving early intervention services appropriate to their individual circumstances, children followed by the "Early Start" program are re-evaluated. If their development has been enhanced to the point that they no longer display significant developmental delays, their cases are closed since they do not qualify for further agency services at that time. However, when test results support continued eligibility for services, they are given a definitive diagnosis of their handicapping condition(s) of mental retardation, cerebral palsy, epilepsy, autism, or similarly impacting disorders based on their present condition and functioning. If the results show their cognitive delays to be of a sufficient magnitude, a child receives a diagnosis of severe or profound mental retardation at this time. The children are then transitioned from the "Early Start" infant stimulation programs provided by the Regional Center and/or the local school system into a regular preschool class, and they are transferred to a regular "School-Age" program caseload for ongoing case management services by the Regional Center. Children whose initial intake occurred after the age of three would be referred directly to the "School-Age" program after diagnosis, without receiving services through the "Early Start" program.

The "Early Start" program has been in operation at Inland Regional Center since October 1, 1993. It replaces the old "Find" program at the agency, and it provides essentially the same services as the "Find" program did, except that it serves a broader range of children. Every child between birth and three years of age who is referred for agency services is followed by the "Early Start" program, whereas the "Find" program focused primarily on the "at risk" children who still had a potential for normal development. Children and families receiving services through the "Early Start" program tend to receive more intensive "hands on" services from agency personnel in addition to the other generic community services available to them. Case managers in this program are required to have a higher education level than most other caseworkers in the agency. They also receive more extensive ongoing training than their agency counterparts in other units. This enables them to meet the child's and family's needs in locating and accessing appropriate services, as well as helping them deal with the physical and emotional ramifications families experience in coping with the new awareness of their child's disability .

Prior to October, 1993, children between birth and five years of age who were found during the intake

process to have a disabling condition that clearly met the agency's eligibility criteria for services were generally transferred almost immediately to the "Infant" program. This unit was designed to provide long-term monitoring of children who were eligible for ongoing services and it provided the same basic services as the present "School-Age" unit. Agency interventions were inclined to be somewhat less intensive since the likelihood of a lifelong disability was fairly certain regardless of the interventions employed. Most of the young severely handicapped children who began receiving services from the agency prior to the implementation of the "Early Start" program were assigned to this unit after the intake process since their disability tended to be clearly evident.

The purpose of this study was to explore the differential impact which the services provided by the "Early Start" and the "School-Age" programs had on the developmental progress of severely and profoundly retarded children. The children who were the focus of this study were between three and six years of age, and began receiving services from Inland Regional Center between the years of 1989 and 1994. For the purpose of this study, they were considered to have participated in the "Early Start" program if they had received services

through either the more intensive old "Find" program or present "Early Start" program for at least six months. The developmental gains of these children were compared to the developmental gains of children who only received services through the less intensive old "Infant" program or present "School-Age" program. The child outcomes were defined as the specific behavioral or functional changes in motor skills, visual skills, and hearing skills that were observed to occur after the time of intake with the agency. Comparisons were made between the child's level of functioning in these areas at the time they began receiving services from the agency and their level of functioning at the time of the study, after both groups were assigned to a regular caseload in the "School-Age" program for ongoing case management services following varying lengths of time in either program. These outcomes were the dependent variables in the study.

Additional information was collected on family demographics, the amount of family interaction with the child, the primary caregiver's emotional reaction to the child, and the child's medical condition and treatment, to assess the degree to which they might have impacted the child's development. These factors were evaluated for their potential as additional independent variables.

RESEARCH DESIGN AND METHODS

This research project was a descriptive study undertaken from the traditional empirical positivist perspective to explore the impact of the early intervention services provided to young severely handicapped children by Inland Regional Center, a community practice social work agency. It utilized a non-equivalent group comparison survey design along with a review of the child's file maintained by the agency to evaluate the differential impact of early intervention services on severely handicapped children. Comparisons were made between children who received services through Inland Regional Center's "Find" or "Early Start" program for varying lengths of time and those who only received regular case management services through the "Infant" or "School-Age" program.

Research Question and Hypothesis

The research question that was addressed in this study was: to what degree is the development of severely handicapped children impacted as a result of receiving early intervention services through Inland Regional Center's "Early Start" program? It was hypothesized that even children with a diagnosis of severe or profound mental retardation would display significantly greater developmental gains in the

targeted areas, than children who received regular case management services in the "School-Age" program, as a result of receiving early intervention services through the "Early Start" program for at least one year.

Sampling

The population of interest for the purpose of this study consisted of all children between the ages of three and six with a diagnosis of severe or profound mental retardation who were clients of Inland Regional Center. To facilitate assessment for the purpose of this study, only children who were living with their families and whose families communicated in English or Spanish were selected for study. All 81 families whose children fit the selection criterion for diagnosis, age, primary language, and residence in the family home were invited to participate in the study.

Data Collection Instruments

The data used in this study were obtained from two sources. A survey instrument was developed in both English and Spanish (Appendices A and B) to collect medical and behavioral information about the child, as well as demographic, behavioral, and attitudinal information about the family. It was reviewed by a worker in the "Early Start" program, a worker in the regular "School-Age" program, and two Spanish-speaking

workers in the "School-Age" program. Suggestions were solicited from them on ways to improve the survey design to facilitate accurate family completion of the form.

Three areas of child development were targeted and assessed from a behavioral perspective through the survey form. Parents were asked to identify their child's competencies in the areas of motor skills, visual skills, and hearing skills. The specific skills selected for inclusion in the survey were skills drawn from the Denver and Bailey infant development screening tools which are commonly used by Inland Regional Center personnel in intake child assessments. Additionally, parents were questioned about their child's overall level of responsiveness in order to obtain a global measure of their developmental potential.

A second source of information for data analysis used in this study was the various professional intake assessments that are kept in the agency file on each child. The social, medical, and psychological intake assessments were reviewed for behavioral information pertaining to the child's competencies in the targeted motor skills, visual skills, and hearing skills <u>at the time of intake</u> with the agency, and for information about any medical conditions impacting the child. This information was used for comparison purposes in order to

determine the amount of developmental and behavioral progress the child made in these areas from the time the agency first began providing services to the family to the present time. Information about dates of case transfer between workers and between different programs was also taken from the file to determine how many different caseworkers each child had been assigned to, and to fix the time of transfer to an ongoing case management unit.

Data Collection Procedure

A total of 81 surveys, 64 (79%) in English and 17 (21%) in Spanish, were mailed to the families identified in the selection process. Each of the families was provided with a pre-addressed, stamped envelope for return of the completed survey form. From this mailing, 27 completed surveys were returned, 20 English surveys and 7 Spanish surveys. Also, 2 additional surveys, 1 English and 1 Spanish, were returned marked "unable to deliver". Two weeks later, a total of 52 families, 43 English-speaking and 9 Spanish-speaking, who had not yet returned the survey were sent a second copy of the form to complete. From this, 11 additional surveys, 5 in English and 6 in Spanish, were returned. This provided a total return of 38 (47%) surveys, 25 (31%) in English and 13 (16%) in Spanish.

Protection of Human Subjects

A cover letter explaining the study (Appendices C and D) and two copies of an informed consent form (Appendix E) were sent to the families along with the survey form. The consent form stated that the family's responses would be kept confidential, and that their participation in the study would not affect the services they were receiving from Inland Regional Center. They were asked to sign and return one copy of the consent form with the completed survey in the return envelope. As the surveys were received, the informed consent form was immediately separated from the survey to maintain the anonymity of the participant's responses.

DATA ANALYSIS

Data were analyzed using "EPI INFO Version 5, A Word Processing, Data Base, and Statistics System for Epidemiology on Microcomputers." Frequencies for the sample as a whole and for each group were obtained, and the quantitative data were tallied by program for comparison. The ANOVA means test, Bartlett's test for homogeneity of variance, and the Mann-Whitney or Wilcoxon Two-Sample (Chi square) statistical tests were used to test the significance of the responses, based on the type of data to be analyzed. A significance level of $p=.05$ was accepted as a conclusive result.

RESULTS

Child Demographics

Forty seven percent of the sample population surveyed responded to the questionnaire, for a total of 38 parents of severely handicapped children. Sixty one percent (23) of the children had a diagnosis of severe mental retardation, and thirty nine percent (15) were diagnosed with profound mental retardation. Seventy four percent (28) of the children participated in the "Infant" or "School-Age" program and twenty six percent (10) received agency services through the "Find" or "Early Start" program, with eight of these ten children receiving services from the program for more than one year. Males outnumbered females in the sample by two (25) to one (13). By age, twenty four percent of the children (9) were three, thirty one percent (12) were four, and forty five percent (17) were five years of age. Ethnically, forty five percent (17) were White, eight percent (3) were Black, forty five percent (17) were Hispanic, and two percent (1) were of other (Asian) ethnicities (See Appendix F, Table 1).

Family Demographics

Sixty six percent (25) of the families spoke English as their primary language, and thirty four percent (13) of the families were Spanish-speaking. The

mean annual income of the families was between $21,000 and $30,000, with fifty six percent grossing less than $20,000 and twenty two percent making over $50,000 a year. There was an average of four other people living in the home with the child, with the average family having changed residences one time since they began receiving services from Inland Regional Center, and having two major life stressors impacting their family. The average primary caretaker of the child had completed 11.5 years of schooling, with thirty one percent not completing high school and thirty four percent completing at least one year of education beyond high school. The families had been assigned to an average of four Inland Regional Center Workers since agency intake (See Appendix F, Table 2).

Factors Related to Development

The children in the study had a mean of five additional impacting physical or medical problems and took an average of two routinely prescribed or "as needed" medications. They averaged fourteen visits to the doctor during the last year, as well as four hospitalizations and two surgeries since intake. The average hospital stay length was three days. Families spent a daily average of ninety seven minutes in focused training with these children (See Appendix F, Table 3).

Overall Changes in Child Development

During the period of time covered by this study, the children in both groups as a whole gained an average of two motor skills, one visual skill, and one hearing skill, with five children showing motor skill losses, nine children showing losses in visual skills, and hearing skill losses shown by five children. They also showed an average increase in purposeful attention-seeking behaviors of three times a day, and a mean increase in duration of responsiveness to family interactions of about eleven minutes. However, forty seven to sixty percent of the respondents did not answer the questions about responsiveness and purposeful attention seeking appropriately, thus reducing the accuracy of these results (See Appendix F, Table 4).

Comparisons of the Two Program Samples

The children in the study who were followed by the "Early Start" program were significantly younger (47.8 months vs. 58.2 months; f=5.22, p=.03) at the present time than those followed by the "School-Age" program, and they went through the intake process significantly earlier (12.4 months vs. 24 months; f=7.74, p=.008). Children in the program for more than a year displayed significantly less motor (2.3 vs. 4.9; f=5.87, p=.02) and hearing (3.3 vs. 4.9; f=4.29, p=.04) skills, as well

as less visual (2.3 vs. 3.5) skills (approaching significance at p=.08) at the time of their intake than the rest of the children. They were also less responsive (0.5 minutes vs. 4.7 minutes, approaching significance at p=.06) at intake. These results were not surprising, since the "School-Age" children were significantly older at intake.

In addition, while the homogeneity of the samples varied (negating the significance of the results when an appropriate analysis was performed), children who participated in the "Early Start" program averaged 4.4 more hospital stays (7.4 vs. 3.0) since intake than children in the "School-Age" program. Moreover, the children had a greater mean number of additional impacting diagnoses (6.4 vs. 5.4), took a slightly greater number of medications (2.6 vs. 2.2), and visited the doctor more frequently (19.1 visits vs. 12.7 visits) during the past year. They also had parents who felt less capable of caring for their children (3.8 vs. 4.1), and parents who felt that their children were more difficult to care for (2.6 vs. 3.0) at the time of intake, as well as parents who <u>presently</u> felt less capable (4.1 vs. 4.7) in caring for their children than the parents of the children in the "School-Age" program. While none of these results approached statistical

significance individually, taken together they suggest that the children receiving agency services through the "Early Start" program tended to be more medically involved than those served by the "School-Age" program.

There were no significant differences in the number of skills acquired or in the changes in responsiveness between the two groups of children during the period under study. However, the children participating in the "Early Start" program averaged more increases in the targeted functional skills than those in the "School-Age" program. They gained an average of 1.7 more motor skills (3.5 vs. 1.8), 0.64 more visual skills (1.38 vs. 0.73), 1.2 more hearing skills (2.0 vs. 0.8), and increased their responsiveness by 0.75 more minutes (12.0 vs. 11.25), based on the ANOVA means test. However, they averaged slightly less daily purposeful attention-seeking behaviors (3.0 vs. 3.3), although this variable had the least number of measurable (15) changes (See Appendix G). No significant interaction effects between the other variables data was collected on were discovered during analysis.

DISCUSSION

The results of the study do not directly support the hypothesis that severely and profoundly retarded children who participated in the "Early Start" program

for at least one year would display significantly greater developmental gains in the targeted areas than the children followed by the "School-Age" program. However, the children followed by the "Early Start" program did not display significantly less skill progress than the children in the "School-Age" program during the study period. This is surprising. One might expect that they would show less progress, as they were significantly younger and showed signs of having more medical complications than the other children. This provides evidence in support of some program impact on them, since they had access to the same generic services in the community as the "School-Age" children did. In addition, the children participating in the "Early Start" program averaged more increases in the targeted functional skills than the other children. While part of these increases might be attributed to the fact that the "Early Start" families provided an average of 13.2 more minutes of training (108.0 vs. 94.8) to their children on a daily basis, it is doubtful that this alone accounted for the observed differences as this result does not even approach the significance level. It is possible that a larger and more thorough matched study that controlled for age and medical condition differences may find the expected result.

Limitations

In analyzing the study results, there are some important limitations which need to be addressed. The reliability of the study is compromised due to the fact that information on skill attainment was taken from different secondary data sources for intake and the present time rather than by the direct observations of the researcher. The various professional assessments contained in the child's agency-maintained file were used as the data source for skill attainment at intake, whereas the data source for the present skill level was the survey completed by the child's parent or primary caretaker. Thus, there was no consistency in assessment and interpretation of these skills between the two observations. However, since the major variables used for the study were readily observable behaviors, the problems created in utilizing and interpreting these secondary data sources should be somewhat minimized.

The validity of the study is also weakened because the results are based on a comparison of two small non-equivalent group samples. In addition, it is possible that something in the children's personal histories other than the interventions provided through the "Early Start" program led to the observed changes. This possibility has not been assessed by this study.

There is also a potential sampling bias in the study since the sample was limited to those families who could read and accurately complete a survey form in either English or Spanish, and who were motivated enough to take the time to respond to the questions. Only forty seven percent of the families surveyed responded to the questionnaire which, as Grinnell (1981) notes, limits the ability to generalize from the findings. Also, although only thirty nine percent (25 out of 64) of the English speaking respondents returned the completed survey, seventy seven percent (13 out of 17) of the Spanish speaking families did so. Thus, the representation by the Spanish speaking population is much greater in the study than in the general population (34% vs. 21%). What impact this may have on the study results is unclear.

Additionally, the questions on purposeful attention seeking behaviors, responsiveness, and focused training received an appropriate response rate of only 25 to 50 percent. Since many of the respondents did not answer the questions appropriately, the reliability of the provided responses is somewhat questionable. A further limitation is that the number of children represented by the various factors that were analyzed was sometimes too small to make reliable between-group comparisons.

One further study limitation was that it compared non-equivalent groups. During analysis, comparisons of several of the variables showed the sample variances to differ significantly, necessitating the use of a nonparametric statistical analysis to correct for this problem. As a result, the certainty of whether the significant effects discovered were due to differences in the interventions the two groups received, or to differences between the groups themselves is reduced.

Implications for Research and Practice

In spite of these shortcomings, the findings in this research illuminate fruitful areas for further study. It would be worthwhile to investigate whether significant differences emerge during the next couple of years between children followed by the "Early Start" program and those who are immediately assigned to a regular caseload, since there is now a more intensive and cooperative outreach effort in place between Inland Regional Center, area hospitals, and local schools. Also, all children under the age of three who receive services from the agency are now served by the "Early Start" program. Because of this there will be a significantly greater sample size of "Early Start" program participants to draw from once the program has been in operation for a few more years. There will also

be a smaller sample size of children who do not receive services through the program because of this change in agency procedures. This will help to even out the size of the two groups, making between-group comparisons more reliable in future research efforts.

Another potential way of expanding this study would be to do longitudinal research on the children in this study with respect to their future skill attainment. This would make it possible to determine the long range effects of early intervention services on development, as well as the compounding effects of early training on the parent's ability to optimize their children's potential at different stages of their lives. Additionally, further exploration of the range and severity of the medical factors affecting their development, as well as the number and types of outside supports that the family has available to them could also help to clarify the impact of these factors on the child's skill attainment.

In another vein, an examination of the types of services the families felt were needed but were not provided by any agency could highlight areas of future service development for agency administrators. Examination of the supports that parents perceived to be the most valuable to them could illuminate intervention

areas that need to be enhanced, based on the parent's perceptions of services and supports they feel would improve their child's development or assist them in providing optimal care for their child. Identification of deficiencies in early intervention efforts is the first step in correcting them, and an ongoing assessment of unmet needs is essential to service development and enhancement.

Steps taken to build on this research effort in these directions will begin to highlight the relative importance of the various aspects of early intervention efforts with the severely handicapped child. A discovery of commonalities of effects regardless of the type or severity of the disability would help to focus and improve intervention efforts with all children by eliminating what doesn't work and providing more of what does. As Shonkoff et. al. (1992) note,

> "from the practical perspective of service delivery, designing individualized intervention strategies for a diverse population of children and families and measuring their effect over time are critical if policy objectives are to be translated into effective programs." (p. 4-5)

Because early intervention programs need to deal with the realities of the cost/benefit ratio, the importance of providing optimally effective services for this diverse population cannot be over-stressed.

Previous intervention evaluation efforts with this population have been specific for the type of disability present, and have used various approaches, limiting the generalizability of the results to other types of severely handicapping conditions. While the present limitations of behavior theory to account for all human behavior and development are apparent, it presently provides a good framework from which to examine and measure the incremental gains of the severely disabled. Because of this, any comprehensive theory of child development will at least need to include elements of behavior theory in it's tenets. It is hoped that the results of this study will provide a beginning step towards a more comprehensive developmental theory that includes rather than excludes the severely disabled population. During the last ten years, many successful efforts at physically integrating the developmentally disabled population into the general population have been achieved. It is time to parallel that physical integration with a beginning theoretical integration of this population into existing developmental theories, and acknowledge the unity of our humanity.

APPENDIX A

EARLY INTERVENTION SURVEY-ENGLISH

1. About how many times has your child seen a doctor during this past year?_____

2. How many times has your child been in the hospital since intake with the Regional Center?____

3. How many days did your child stay in the hospital?

   Shortest _____ Longest _____ Average _____

4. How many surgeries has your child had since intake with the Regional Center?_____

5. How many times have you moved from the time of intake with the Regional Center until now?_____

6. What motor skills does your child have now? (mark all that apply)

___unable to move	___throws objects
___lifts head up	___sits without help
___rolls over	___scoots or crawls
___holds objects	___stands while holding on
___reaches for objects	___stands without help
	___walks without help

7. What visual skills does your child have now? (mark all that apply)

___unable to see	___looks for hidden things
___smiles back at you	___examines objects
___looks at objects	___chooses 1 of 2 objects
___watches moving toys	___reacts to strangers

8. What hearing skills does your child have now? (mark all that apply)

___unable to hear	___turns towards sounds
___reacts to sounds	___looks for sound source
___listens to sounds	___makes sound with a toy
___responds to voices	___responds to words
	___follows simple request

9. About how many times will your child try to get your attention each day on purpose?

   when you came to the Regional Center____ now____

10. How many minutes will your child interact with you on the average before stopping or getting upset?

    when you came to the Regional Center____ now____

11. About how much total time are you and the other members of your household able to spend in focused activities with your child each day?

    Number of minutes _____

12. How easy do you think it is for you to take care of your child? (1=very hard to 5=very easy)

    at intake 1 2 3 4 5 at present 1 2 3 4 5

13. How capable do you feel in caring for your child? (1=not capable to 5=very capable)

    at intake 1 2 3 4 5 at present 1 2 3 4 5

14. Your ethnicity? White Black Hispanic

    Native American Asian Other _____

15. What is the highest grade you finished in school?__

16. How many people are living in your house now?_____

17. What is your total gross household income per year?

    ___Under $10,000
    ___$10,000--$20,000
    ___$21,000--$30,000
    ___$31,000--$40,000
    ___$41,000--$50,000
    ___Over $50,000

18. What major events have affected your household since the time of intake (births, deaths, divorces, marriages, loss or changes in employment, large changes in your finances, major surgeries, major injuries, major illnesses, etc--please list the event and the number of times each kind of event occurred since you came to the Regional Center)?

    _____

    _____

    _____

19. How helpful (1=not helpful to 5=very helpful) has contact with Regional Center workers been to you?

    1 2 3 4 5

Thank you for your assistance with this research.

APPENDIX B

EARLY INTERVENTION SURVEY-SPANISH

1. Numero de veces en este año pasado que su hijo(a) vio a un doctor?_____

2. Numero de veces que su hijo(a) a sido hospitalizado(a) desde que aplico por el proceso de Intake la entrevista initial en el Centro Regional?____

3. Cuantos dias se quedo su hijo(a) en el hospital?

   Lo menos _____ Lo mas _____ Promedio _____

4. Numero de operaciones hechas a su hijo(a) desde que aplico para el proceso de Intake la entrevista initial con el Centro Regional?_____

5. Cuantas veces se a cambiado de vivienda desde que aplico para el proceso de Intake con el Centro Regional? _____

6. Que habilidades fisicas tiene su hijo(a)?
   (marque todas las que apliquen):
   ___no se mueve
   ___levanta la cabeza
   ___se da vuelta
   ___agarra objetos
   ___trata de agarrar objetos
   ___avienta objetos
   ___se sienta sin que lo/la ayuden
   ___gatea o se arrastra
   ___se para con el apoyo de algo
   ___se para solo(a)
   ___camina sin ayuda

7. Que habilidades visuales tiene su hijo(a)?
   (marque todas las que apliquen):
   ___no mira
   ___reacciona con sonrisa
   ___mira los objetos
   ___sigue objetos que se mueven
   ___busca cosas que estan escondidas
   ___examina objetos
   ___escoje 1 de 2 objetos
   ___reaciona hácia personas desconocidas

8. Que habilidades de oir tiene su hijo(a)?
   (marque todas las que apliquen):
   ___no oye
   ___reacciona cuando oye ruidos
   ___oye los ruidos
   ___responde a las voces
   ___voltea hacia los ruidos
   ___busca de donde viene el ruido
   ___hace ruido con los juguetes
   ___responde a las palabras
   ___hace lo que piden

9. Aproximadamente el numero de veces al dia que su hijo/a a proposito trata de atraer su atencion?
   Cuando vino a el Centro Regional _____ Hoy _____

10. Cual es el promedio de minutos al dia tiempo que su hijo(a) le responde a usted antes de parar o de enojarse?
Cuando vino a el Centro Regional _____ Hoy _____

11. Cuanto tiempo en total pasan al dia todos los que viven en su casa haciendo actividades enfocadas en su nino(a) cada dia?
Numero de minutos _____

12. Que tan facil piensa que es para usted el cuidado de su hijo(a)? (1=muy dificil a 5=muy facil) :

desde "Intake" 1 2 3 4 5 presentement 1 2 3 4 5

13. Que tan capaz se siente usted para cuidar de su hijo(a)? (1=no muy capaz a 5=muy capaz)

desde "Intake" 1 2 3 4 5 presentement 1 2 3 4 5

14. Su etnicidad? Blanca Negra Hispana

Americano Nativo Asiatico Otro _____

15. El grado mas alto que completo usted en la escuela?____

16. Numero de personas que viven en su casa? _____

17. Ingreso total de su casa por ano?

___menos de $10,000
___$10,000--$20,000
___$21,000--$30,000
___$31,000--$40,000
___$41,000--$50,000
___Mas de $50,000

18. Otras influencias mayores que han afectado a su casa desde el tiempo de "Intake" (nacimientos, matrimonios, muertes, divorcios, perdidas o cambios de empleo, daños mayores, operaciones mayores, enfermedades mayores, grandes cambios financiales, etc, por favor ponga toda clase de cambios y el numero de veces que hubo un cambio o ocurio desde el tiempo de "Intake")?

_____

_____

19. Que tanta ayuda le han dado los trabajadores del Centro Regional? (1=no ayudaron a 5=ayudaron bastante)

1 2 3 4 5

Muchas gracias por su asistencia en esta encuesta.

APPENDIX C
COVER LETTER-ENGLISH

January 1, 1995

Dear Parent/Guardian,

I am asking for your help with a research project which focuses on the development and needs of children who are severely disabled. I am a masters student at California State University, San Bernardino, being supervised by Dr. Nancy Mary, professor of Social Work. I am also a caseworker at Inland Regional Center, and I have worked with people who are severely disabled for several years. I will be looking at the development of children with severe disabilities from the time of intake, when they first became clients of our agency, to the present time. I will share the general results of this research with our agency's administrative personnel, but I promise you that your answers will be kept completely confidential.

The attached survey form, which will take about 5 to 10 minutes to complete, examines how different things influence the rate of development of children with severe disabilities. Your participation in this study will help caseworkers and other professionals who work with these children and their families to better meet their needs, but it is completely voluntary and will in no way affect the services you currently receive or will receive in the future from Inland Regional Center. It would help if the person who spends the most time taking care of your child is the one who fills out the survey.

I realize that your time is valuable, and you may want to put this survey aside until you have more time. However, my research time is very limited and I need all the forms back by my deadline of 1-20-95, so please try to return it to me in the next day or two. Your signed consent form, which is attached to the survey form, also needs to be returned so I can get additional information from the child's file. The other copy of the form is for you to keep. If you have any further questions or comments, or wish to find out about the results of this study, please feel free to contact me through the CSUSB Social Work Department, (909) 880-5501. I appreciate your assistance with this project, and I hope it will do something to help those we all care about. Thank you.

Sincerely,

Terry Stacy, MSW Student

APPENDIX D
COVER LETTER-SPANISH

Enero 1, 1995

Estimado Padre/Tutor,

Le estoy pidiendo su ayuda para una encuesta que esta enfocado en el desarollo y necesidades de niños(as) que estan severamente incapacitada(o). Yo soy una estudiante del programa de Maestria en la Universidad del Estado de California, San Bernardino, siendo supervisada por la Dr. Nancy Mary, profesora de Trabajo Social. Tambien soy una trabajadora social en el Centro Regional de Inland, y yo he trabajado con personas que estan severamente incapacitados por varios años. Yo estare viendo el desarollo de los niños(as) que estan severamente incapacitadas(os) desde la entrevista initial (Intake), desde que fueron clientes por primera vez de nuestra agencia, a el presente. Yo voy a compartir esta encuesta y compartire los resultados generales con nuestro personal administrativo de nuestra agencia, pero yo le aseguro que sus respuestas seran confidenciales.

La encuesta que esta adjunto, que le tomara como cinco o diez minutos para completar, examina como diferentes cosas influyen el grado de desarrollo del niño(a) con incapacidades severas. Su participacion en esta encuesta ayudara a los trabajadores y a otros profesionales quienes trabajen con estos niños(as) y sus familias para mejorar nuestros servicios y poderlos ayudar mejor, pero es completamente voluntario y de ninguna manera affectara los servicios que usted esta recibiendo o recibira en el futuro de parte del Centro Regional de Inland. Nos ayudaria bastante que la persona quien pasa mas tiempo cuidando el niño(a) sea la persona quien llene esta encuesta.

Yo se que su tiempo es importante, y tal vez usted quiera poner esta encuesta a un lado hasta que usted tenga mas tiempo. Pero, mi tiempo de estudio es muy limitado y yo necesito entregar las formas para el dia 1/20/95, asi que por favor trate de regresarmela en los proximos dos dias. Su forma firmada de consentimiento, que esta adjunta con la encuesta, tambien la necesita regresar para poder obtener mas informacion del archivo de su niño(a). La otra copia de la forma es para que usted se quede con ella. Si usted tiene preguntas o comentarios, o desea los resultados de esta encuesta, por favor sientase libre de llamarme al Departamento de Trabajos Sociales (CSUSB Social Work Department), (909) 880-5501. Le agradezco su asistencia en este proyecto, y espero que esto les ayude a esas personas a las quienes estimamos. Gracias.

Sinceramente,

Terry Stacy, Estudiante de MSW

APPENDIX E
INFORMED CONSENT-ENGLISH AND SPANISH

Informed Consent UCI#: _____

I acknowledge that I have been informed of and understand the nature and purpose of this study. I freely consent to participate, with the agreement that this consent form will be removed from my questionnaire before the survey is processed. I understand that the confidentiality of my responses will be maintained, and that my participation in this survey will in no way affect the services I am currently receiving or will receive in the future from Inland Regional Center.

_____ _____
Parent/Guardian Date

Consentimiento Informado Numero de UCI: _____

Yo reconozco que e sido informada(o) y entiendo la naturaleza y el proposito de esta encuesta. Yo libremente consiento a participar, y estoy de acuerdo a que esta forma de consentimiento sea quitada de mi questionario antes que la encuesta sea procesada. Yo entiendo que mis respuesta seran mantenidas completamente confidenciales, y mi participacion en esta encuesta de ninguna manera afectara los servicios que estoy recibiendo o recibire en el futuro del Centro Regional de Inland.

_____ _____
Padre/Tutor Date

APPENDIX F

TABLE 1
CHILD DEMOGRAPHICS

	EARLY START	INFANT	TOTALS	MISSING DATA
Diagnosis				
Severe Retardation	6	17	23(61%)	
Profound Retardation	4	11	15(39%)	
TOTALS	10	28	38(100%)	0(0%)
Program				
Infant/School-age	0	28	28(74%)	
Find/Early Start	10	0	10(26%)	
TOTALS	10	28	38(100%)	0(0%)
Gender				
Male	7	18	25(66%)	
Female	3	10	13(34%)	
TOTALS	10	28	38(100%)	0(0%)
Age				
3	6	3	9(24%)	
4	2	10	12(31%)	
5	2	15	17(45%)	
TOTALS	10	28	38(100%)	0(0%)
Ethnicity				
White	5	12	17(45%)	
Black	0	3	3(8%)	
Hispanic	4	13	17(45%)	
Other	1	0	1(2%)	
TOTALS	10	28	38(100%)	0(0%)
Number of IRC Workers (due to staff or program changes)				
1 to 2	2	8	10(26%)	
3 to 4	3	10	13(34%)	
5 to 6	4	7	11(29%)	
7 to 8	1	3	4(11%)	
TOTALS	10	28	38(100%)	0(0%)

APPENDIX F

TABLE 2
FAMILY DEMOGRAPHICS

	EARLY START	INFANT	TOTALS	MISSING DATA
Survey Language				
English	6	19	25(66%)	
Spanish	4	9	13(34%)	
TOTALS	10	28	38(100%)	0(0%)
Income				
Under $10,000	2	5	7(20%)	
$10,000 - $20,000	4	9	13(36%)	
$21,000 - $30,000	1	4	5(14%)	
$31,000 - $40,000	0	0	0(0%)	
$41,000 - $50,000	1	2	3(8%)	
Over $50,000	1	7	8(22%)	
TOTALS	9	27	36(100%)	2(5%)
Number Living in Home				
2 to 3	2	4	6(17%)	
4 to 5	5	12	17(47%)	
6 to 7	2	8	10(28%)	
8 to 9	0	3	3(8%)	
TOTALS	9	27	36(100%)	2(5%)
Number of Residence Moves				
0	4	14	18(49%)	
1 to 2	6	8	14(38%)	
3 to 4	0	4	4(11%)	
5 or more	0	1	1(2%)	
TOTALS	10	27	37(100%)	1(2%)
Number of Major Life Events				
0 to 2	8	18	26(70%)	
3 to 5	1	4	5(14%)	
6 to 8	1	2	3(8%)	
over 8	0	3	3(8%)	
TOTALS	10	27	37(100%)	1(2%)
Highest Grade Completed				
1 to 6	3	2	5(14%)	
7 to 11	1	5	6(17%)	
12	3	9	12(35%)	
13 to 15	1	6	7(20%)	
16 and over	1	4	5(14%)	
TOTALS	9	26	35(100%)	3(8%)

APPENDIX F

TABLE 3
FACTORS RELATED TO DEVELOPMENT

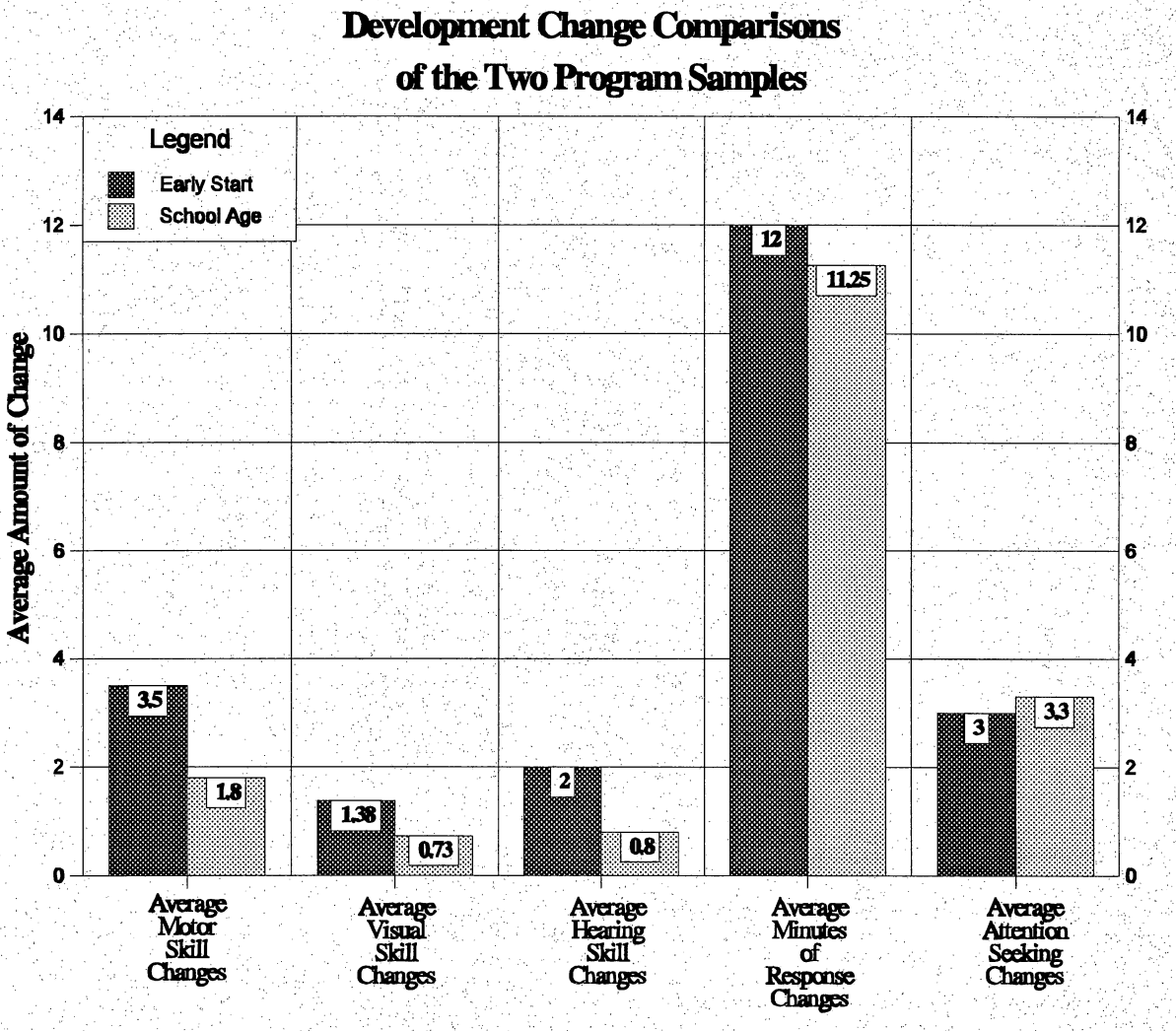
	EARLY START	INFANT	TOTALS	MISSING DATA
No. of Additional Diagnoses				
0 to 3	3	7	10(26%)	
4 to 7	3	14	17(45%)	
over 7	4	7	11(29%)	
TOTALS	10	28	38(100%)	0(0%)
No. of Prescriptions				
0	2	8	10(26%)	
1 to 3	4	16	20(53%)	
4 to 6	4	2	6(16%)	
over 6	0	2	2(5%)	
TOTALS	10	28	38(100%)	0(0%)
No. of Doctor Visits				
0 to 7	4	9	13(34%)	
8 to 16	2	11	13(34%)	
over 16	4	8	12(32%)	
TOTALS	10	28	38(100%)	0(0%)
No. of Hospitalizations				
0	5	11	16(42%)	
1 to 6	2	13	15(39%)	
over 6	3	4	7(19%)	
TOTALS	10	28	38(100%)	0(0%)
Avg. Hospital Stay Length				
0 to 3	6	17	23(66%)	
4 to 7	3	6	9(26%)	
over 7	0	3	3(8%)	
TOTALS	9	26	35(100%)	3(8%)
No. of Surgeries				
0	5	13	18(48%)	
1 to 2	4	8	12(31%)	
3 to 4	0	4	4(11%)	
5 to 6	1	1	2(5%)	
over 6	0	2	2(5%)	
TOTALS	10	28	38(100%)	0(0%)

APPENDIX F

TABLE 4
CHANGES IN CHILD DEVELOPMENT

	EARLY START	INFANT	TOTALS	MISSING DATA
Amount of Daily Training				
0 to 30 minutes	1	4	5(18%)	
31 to 60 minutes	2	4	6(21%)	
61 to 90 minutes	0	4	4(14%)	
91 to 120 minutes	3	5	8(29%)	
over 120 minutes	1	4	5(18%)	
TOTALS	7	21	28(100%)	10(26%)
Changes in Daily Attn Seeking				
No change	0	5	5(33%)	
Increase of 1-5 times	2	6	8(54%)	
Increase over 5 times	0	2	2(13%)	
TOTALS	2	13	15(100%)	23(60%)
Changes in Responsiveness				
Loss of responsiveness	1	1	2(10%)	
No change	0	5	5(25%)	
Increase of 1-10 times	1	5	6(30%)	
Increase of 11-20 times	3	2	5(25%)	
Increase over 20 times	0	2	2(10%)	
TOTALS	5	15	20(100%)	18(47%)
Motor Skill Changes				
Loss of 1 to 4 skills	1	4	5(13%)	
No change	2	7	9(24%)	
Gain of 1 to 4 skills	4	12	16(42%)	
Gain of 5 to 8 skills	3	5	8(21%)	
TOTALS	10	28	38(100%)	0(0%)
Visual Skill Changes				
Loss of 1 to 4 skills	3	6	9(24%)	
No change	0	6	6(16%)	
Gain of 1 to 3 skills	5	14	19(50%)	
Gain of 4 to 6 skills	2	2	4(10%)	
TOTALS	10	28	38(100%)	0(0%)
Hearing Skill Changes				
Loss of 1 to 4 skills	3	2	5(13%)	
No change	1	9	10(26%)	
Gain of 1 to 3 skills	3	14	17(45%)	
Gain of 4 to 6 skills	3	3	6(16%)	
TOTALS	10	28	38(100%)	0(0%)

APPENDIX G


Development Change Comparisons
of the Two Program Samples
Legend
Early Start
School Age
Average Amount of Change
0
2
4
6
8
10
12
14
3.5
1.8
1.38
0.73
2
0.8
12
11.25
3
3.3
Average Motor Skill Changes
Average Visual Skill Changes
Average Hearing Skill Changes
Average Minutes of Response Changes
Average Attention Seeking Changes

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